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ORIGINAL ARTICLE

N = many me's: self-surveillance for Precision Public Health

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Abstract This paper focuses on Precision Public Health (PPH), described in the scientific literature as an effort to broaden the scope of precision medicine by extrapolating it towards public health. By means of the "All of Us" (AoU) research program, launched by the National Institutes of Health in the U.S., PPH is being developed based on health data shared through a broad range of digital tools. PPH is an emerging idea to harness the data collected for precision medicine to be able to tailor preventive interventions for at-risk groups. The character of these data concern genetic identity, lifestyle and overall health and therefore affect the 'intimacy' of personhood. Through the concept of biological citizenship, we elucidate how AoU and its recruitment tactics, by resonating 'diversity', at the same time appeal to and constitute identity, defining individuals as 'data sharing subjects'. Although PPH is called for; the type of bio-citizenship that is enacted here, has a particular definition, where participant recruitment focuses on 'citizenship' in terms of empowerment (front), it is the 'bio' prefix that has become the main focus in terms of research. i.e. biosubjectivities vs biocapital. This raises the question whether the societal challenges that often underlie public health issues can be sufficiently dealt with based on the way 'diversity' is accounted for in the program. We suggest that the AoU still risks of harming underrepresented groups based on the preconditions and the design of the program.

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Introduction

> What lies inside all of us is more than data. It's life. Its more than insight and medical research. Its vision and honor and compassion. What's flowing through Americas veins is its' diversity.

– this is the core message of the "AllofUs anthem-video" to engage Americans with the All of Us (AoU) research program that was previously known as the Precision Medicine Initiative. While data are the outcome of the scientific method and digital instruments the video makes it seem as though data concern something more sacred; *Americas diversity*. By means of this program, the National Institutes of Health (NIH) intend to further develop precision medicine. One of the objectives described in the scientific literature is to develop Precision Public Health (PPH; Whitsel et al. 2018). 'Precision' can be explained as the aim to use large amounts of data to generate more precise lifestyle interventions or treatment. It entails the convergence of research and preventive medicine which some authors suggest sets the stage for public health interventions (Dolley 2018). In this article we address the question whether public health policy can be developed based on AoU while at the same time sufficiently addressing the perceived risk of harming specific groups as is described in the PPH literature (Lyles et al. 2018).

Whilst we base our analysis on literature about the relation between data donation and PPH, our core argument relies on an analysis of the discourse used by the NIH and the AllofUs initiative. Here, our methodology, is based on the Foucauldian notions of biopolitics and biocitizenship: Foucault's moral and political analysis, as it is expressed through his notion of biopolitics, consists of an analysis an articulation of the dispositives (the various institutional, technological and administrative mechanisms and structures which enable and enhance particular research practices). This allows us to explore the tensions between the vocabulary that is explicitly used in stated positions of actors on the one hand and the actual practices of these various stakeholders on the other. Subsequently, we further elucidate these tensions by drawing comparisons between what is happening today and various historical precursors. In other words, we combine a diagnostic of the present with an autopsy of the past.

First, we will describe what Precision Medicine is and how PPH is currently emerging. Additionally we explain how the AoU program intends to protect its participants based on the AoU consent form and the program design. Second, we will introduce a notion of biocitizenship before we turn to the AoU, where we critically assess the notion of bio-citizenship enacted in the program. We show how the AoU program explicitly foregrounds identity issues to motivate participants to donate their data. We argue that by framing data as the currency of 'life'

in its biological sense, it fails to acknowledge life in terms of citizenship which is crucial to the success of public health initiatives i.e. being a member of society, with its rights and duties.

Precision Public Health

In 2010, the leaders of the Food and Drug Administration (FDA) and the National Institute of Health (NIH) in the U.S., Margaret Hamburg and Francis Collins, shared their vision of personalized medicine stating that they were building "a national highway system for personalized medicine" (Hamburg and Collins 2010, p. 304). This research infrastructure was officially launched early 2015 as the Precision Medicine Initiative and subsequently gave rise to the AoU program (Collins and Varmus 2015). Precision Medicine focuses on identifying "which approaches will be effective for which patients based on genetic, environmental, and lifestyle factors" (NIH 2015). Although it builds on the achievements of genomics science, it has broadened its scope. Currently, Precision medicine entails the idea that personal 'big data' will help us to manage our health, as demonstrated by key examples such as the integrative personal omics profiling (iPOP) method developed by Michael Snyder, or the P100 wellness study by Leroy Hood. Both initiatives employ personal data clouds to identify "early transition to disease states" (Li et al. 2017; Price et al. 2017, p. 747).

The newness of the AoU compared to other initiatives was explained by Collins and Varmus in terms of scale in a publication entitled 'A New Initiative on Precision Medicine' (Collins and Varmus 2015). In this paper, they emphasized the possibility to differentiate between individuals because of technological developments that involve large-scale (biological) databases, biomarker profiling, and bio-computation (Collins and Varmus 2015). In that same year, moreover, Nicholas Schork discussed the necessity of one-person- trials in a *Nature* article. According to Schork, time was ripe for such trials for three reasons: (a) the rapidly expanding—omics fields, allowing for molecular profiling; (b) the increasing amount of cheap and efficient devices to collect data, such as the apple watch; and (c) the growing support by the government for patient engagement in medicine (Schork 2015a). The following year, *Nature* published a review by Ashley (2016) called "Toward precision medicine", who speaks of 'genomic data' and demands more refined algorithms for precision analysis (Ashley 2016). Such publications helped to set the stage for a newly emerging field of biomedical research that is highly digitalized and dependent on big data operations, their algorithms and deliverables. In an attempt to increase scale, the NIH is now attempting to build a national research cohort of one million or more U.S. participants. The AoU website explains that:

> Americans are engaging in improving their health and participating in health research more than ever before, electronic health records have been widely adopted, genomic analysis costs have dropped significantly, data science has become increasingly sophisticated, and health technologies have become mobile. All of Us is a participant-engaged, data-driven enterprise supporting research at the intersection of human biology, behavior, genetics, environment,

> data science, computation and much more to produce new knowledge with the goal of developing more effective ways to treat disease. (NIH, n.d.)

As indicated, the AoU program invites participants to share health surveys, biosamples, and electronic health records (EHRs; (Whitsel et al. 2018). The quote above emphasizes once more that developments in Digital Health set the stage for Precision Medicine which, in its current form, is converging biomedical research, preventive medicine, and technological innovation. This is also connected with another concurrent development, moreover: the need for such initiatives to become 'participant-engaged' to collect the data. Thus, these initiatives become dependent on the willingness of participants to share samples and data (Blasimme and Vayena 2016).

The promises of precision medicine, together with the development of a national database, has led to the emergence of PPH which involves practices to predict and understand public health risks based on the data gathered for precision medicine (Dolley 2018; Lyles et al. 2018). It entails both the third pillar of P4 medicine (*prevention*) and the fourth pillar of the model (*participation*), moving beyond the current model of clinical trial participation and embracing "citizen-driven trials" (Blasimme and Vayena 2016; Hood and Friend 2011). In 2015, the Centers for Disease Control and Prevention began to discuss and explore PPH. "Precision" is understood here as the application of emerging technologies such as bioinformatics and digital epidemiology and the development of policies and targeted public health programs (Khoury 2015). In 2016, The Bill and Melinda Gates Foundation hosted a conference entitled "Precision Public Health: The First 1,000 Days' and called for more robust surveillance (Chowkwanyun et al. 2018; Dolley 2018). Soon, preliminary definitions of PPH followed, such as— "the application and combination of new and existing technologies, which more precisely describe and analyse individuals and their environment over the life course, to tailor preventive interventions for at-risk groups and improve the overall health of the population" (Weeramanthri et al. 2018, p. 2). There seem to be two visions at work in PPH: one in which the term precision means it will allow researchers to refine subgroups based on genetic traits; the other in which the term means reframing and broadening precision medicine beyond 'omics' (e.g., genomics, proteomics, metabolomics). In the latter version, genomics is only one of multiple methods to generate vast amounts of data to serve precision ends (Chowkwanyun et al. 2018; Lyles et al. 2018).

As described in a previous publication, Precision Medicine can be interpreted as developing biomarker-based health promotion, which raises the question whether its logic can scaled up for PPH (Vegter 2018). The former ties in with a more fundamental discussion held in Nature Biotechnology where Vogt et al. respond to Leroy Hoods P100 Wellness study; urging researchers in precision medicine to substantiate 'actionable evidence' (Vogt et al. 2018). The study published by Price et al. describes how complex—omics profiling and continuous monitoring using Fitbit™ led to lifestyle recommendations (Price et al. 2017). The authors claimed that;

> For each measurement in an individual that was outside the clinical reference range recommended by the clinical laboratory, the coach would recommend

> lifestyle changes that have been previously demonstrated to produce improvements in that marker (Price et al. 2017, p. 753).

The focus on biomarkers, i.e. the reliance on bio-molecular endpoints rather than phenotypic endpoints, has been criticized by Vogt et al. who claim that this type of research leads to over-diagnosing and contributes to the "pathologization" of individuals (Vogt et al. 2018). Which is the exact opposite of what a public health measures need to achieve.

A similar practice is suggested in the AoU program where it is stated in the consent form that participants might be asked to start using wearables.

> We will gather data from you through the All of Us app and/or website. You may be asked to wear a fitness tracker. There is a risk to your privacy whenever you use an app, website, or fitness tracker. In general, there is no additional risk to your privacy if you use any of them as part of All of Us. That said, we will be gathering many different types of data in your All of Us record. If there is a data breach, there may be additional risk to your privacy because of the amount of data in your All of Us record (consent form AllofUs, 2018, p. 6).

Ironically, PPH has its roots in the call for one-person-trials that tends to focus on tailored lifestyle recommendations and thus explicitly frames population health as improving the health of multiple *individuals* (Chowkwanyun et al. 2018; Schork 2015b). Additionally, it is emphasised that PPH does not explicitly address the vulnerability of specific groups as the result of structural factors such as social class, ethnic background, gender and sexual identity and properties of shared surroundings (Chowkwanyun et al. 2018; Horton 2018). This is why we refer to PPH as a step from 'n = me' to 'n = many me's'. Taylor-Robinson et al. likewise argue that the idea to take the step from 'personalized' to 'population-based' approaches is a false dichotomy, calling it naively optimistic. They emphasize how successful public health interventions always entail a combination of the two (Taylor-Robinson and Kee 2018).

The result of the PPH debate is a call for stakeholder involvement. "Participant-generated health data collection processes will never be successful unless stakeholders help to set the agenda and are assured that the information is not used to worsen the stigmatization or profiling of individuals/groups" (Lyles et al. 2018, p. 2). (This criticism has been taken up by the AoU which we will discuss in the 'Identity' section of this article.) Similarly, on the basis of literature review on the role of Big Data in PPH, Shawn Dolley and colleagues concludes: "The community should be watching for overreliance on big data-driven approaches that lead to decreases in radical whole population solutions that increase baseline health norms". Nevertheless, they deem PPH to be promising and expect that:

> Future precision public health will be transformative. It will include new applications, modifications, and uses of today's assets, including social media and communication platforms, unmanned aerial vehicles, mobile applications, mobile sequencing, selfscreening, sensors, vaccine or drug internet-of-things inventions, and more. Tomorrow, we could be looking up, wondering if a high-

> resolution satellite is mapping our neighbourhood to predict the path of an infectious disease, or if a drone is approaching with a targeted intervention. With future applications of precision public health and the speed of big data adoption, tomorrow's new public health students and young practitioners soon won't think of the discipline as precision public health. They will only think of it as public health (Dolley 2018, p. 7).

Considering the sensitive nature of biomedical data, both the statement that PPH will be transformative and the promise to use ever more technological solutions demand closer inspection. The ways in which data can be collected and the countless tech entrepreneurs that are involved in finding 'solutions' should be pitched against this so-called stakeholder involvement and the empowerment rhetoric continued by the AoU.

To understand this for the AoU program more thoroughly we've turned to the consent form which describes how AoU will create both a public database and a scientific database (consent form AllofUs, 2018). The public database is said to be about 'groups' while the scientific database will have individual-level data and samples. Stating the following about access to the scientific database:

> We will also create a scientific database. The scientific database will have individual-level data and samples. Access to this database will be controlled. Researchers will have to be approved by All of Us to use this database. These researchers may be from anywhere in the world. They may work for commercial companies, like drug companies. They may be citizen scientists. Citizen scientists are people who do science in their spare time. P5

When the reader might be concerned whether his or her data end up in developing commercial products the consent form clearly states;

> Researchers will use your data to make discoveries. If any of their studies lead to new tests, drugs, or other commercial products, you will not get any profits. These inventions will be the property of the researchers who develop them.

Additionally it says data are no longer protected by *Health Insurance Portability and Accountability Act of 1996* (*HIPAA*).[1] The consent form makes it really clear, the AoU serves as a gatekeeper, an intermediary or platform, that exchanges data for 'indirect benefit'; "you may learn about your health" (p. 8). And in case participants are concerned with the sacredness of 'diversity' in the way the AllofUs-anthem suggests; the consent form does warn about the vulnerability of specific group identities*;*

> Researchers will use basic facts like your race, ethnic group, and sex in their studies. This data helps researchers learn if the things that affect health are the same in different groups of people. These studies could one day help people of the same race, ethnic group, or sex as you. However, there is a risk that others

[1] HIPAA is United States legislation that provides data privacy and security provisions for safeguarding medical information.

> could use this data to support harmful ideas about groups (consent form AllofUs, 2018, p. 6).

Taking into account that the consent form states that the collected data will be used for profit, might harm you as a group, that participants won't receive direct health benefits and personal information is no longer protected by patient privacy rules urges us to pose the question; Why is it that individuals willingly join the program? Based on our research we theorize people are incited to donate their data because a particular notion of biocitizenship is enacted within the AoU program that appeals to group identities and notions of solidarity that are specifically relevant in this day of age. Before going into detail about the way in which the AoU program situates diversity as being fundamental to the success of precision medicine we first provide a short theoretical framework for understanding such trends in terms of biopolitics.

Bio-citizenship

During the past decades, authors such as Nicholas Rose, Carlos Novas and Paul Rabinow have developed a network of interrelated concepts which build on the oeuvre of the French philosopher Michel Foucault but are used to analyse emerging technologies in contemporary health care (Rabinow 1996; Rose 2007; Rose and Novas 2008). This notably includes the concept of biopower. Biopower is the power exercised by nation states or other governmental bodies over their citizen through their biology, targeting their bodies, their biological traits. Building on Foucault, these authors have analysed how these technologies no longer rely on discipline and punishment, but rather on contemporary notions of government, control and regulation. According to Foucault, techniques of bio-surveillance have expanded drastically in modern societies. He already perceived "an explosion of numerous and diverse techniques for achieving the subjugations of bodies and the control of populations" (Foucault 1976, p. 140). To further explore this issue, he coined the term biopolitics. According to Foucault, "Biopolitics deals with the population […] as a political problem […] that is at once scientific and political, as a biological problem and as power problem" (Foucault 1976, p. 245). It describes how biopower is exercised concretely, which mechanisms are deployed, on the basis of which technologies and strategies to manage the processes of life in society. This includes regimes of power and control, the societal role of knowledge and the processes through which subjecthood is constituted.

According to authors such as Paul Rabinow and Nicholas Rose, biopower does not only entail negative aspects, nor should it be merely interpreted in terms of top-down hierarchical power relations. These emerging technologies may also contribute to empowering individuals or to redefining relationships between individuals and to society. Rose and Rabinow specifically focus on novel developments in biotechnology that have established a basis for new relations between identity, biology, technology and society. Rose developed the concept of bio-citizenship on the basis of Foucault's work (Rose 2007). The term had been used before, by Petryna (2002), but in a more specific sense: to address the biological damage inflicted on the population in the Chernobyl

case. Rose extrapolated the concept to address the impacts of emerging technologies more broadly. Tamar Sharon likewise points out that a Foucauldian critique, although often emphasising the disciplinary and repressive aspects of health promotion, should not overlook the creative and productive aspects of biotechnology; like becoming a participant in the AoU program (Sharon 2014, p. 63). Sharon points out that a one-sided use of the Foucauldian repertoire may prevent us from seeing how engagements with these technologies, such as self-tracking and genomic testing for example, may in fact resist disciplinary narratives and allow active appropriation of the technological mediations that contribute to the constitution of the self (Sharon 2014, p. 63).

The biopolitics concept exemplifies how the prefix 'bio' is currently added to a plethora of terms such as -citizenship, -power, -society, -value, -labour, -economy etc. to analyse societal dimensions of life sciences research, innovation, regulation and communication (Birch 2017). Although the prefix 'bio' is clearly in vogue, we do believe that the type of analysis conducted by authors such as Rose, Rabinow, Novas and others allows us to map the different, albeit often hidden interests, intentions and drivers that underlie the development and implementation of novel technologies in the contemporary life sciences. Birch warns academics that show affinity for this type of analysis that the term biocitizenship is on some ways blindsided. It ignores several things such as continuing external disciplinary pressures; other forms of non-genetic and non-genomic (i.e. non-biomedical) knowledge and discourse; and critiques of bioscience and biotechnology (Birch 2017; Plows and Boddington 2006). Birch criticism suggest we should not look at participants of the AoU as self-governing, biological citizens fully aware of the most recent scientific developments, but rather as being subjected to a particular notion of citizenship by the intermediaries of science and publics. While participants themselves might operate in a completely different reality.

In recent years, moreover, this type of analysis has evolved into a substantial discourse in its own right. In 2008, for instance, Deborah Heath and colleagues described the blurring boundaries between state and society, as well as between private and public interest, as a result of the ongoing reconfiguration of genetic science and the public sphere (Heath et al. 2008). Now, a decade later, due to ongoing developments in big data science, their analysis still seems highly relevant. They link postmodern theories of subjectivity (Foucault 1986) to feminist moral philosophy and argue that these are complementary in their analysis of genetic citizenship (Heath et al. 2008). Their work highlights the interconnection between individual rights and responsibilities on the one hand and public conditions and enabling infrastructures on the other (Heath et al. 2008, p. 157). In this article, we likewise argue that articulating the drivers and infrastructures that enable the introduction of novel technologies (in our case: in PPH) will aid the moral assessment of these developments, while it may also allow us to develop tools for critical self-analysis by stakeholders involved in such developments. In this spirit, this paper will examine what notion of bio-citizenship is enacted by the AoU program, and how this notion organizes responsibility in the context of PPH. Bio-citizenship today is enabled by digital health, as biomedicine has increasingly become data-driven. Yet, what remains rather unexplored is to what extent data donors may influence or even determine the use and agenda-setting of PPH. To what extent does data sharing also entail benefit sharing?

Identity

One important aspect of the AoU program is that it wants to reach out to 'underrepresented groups' and to respect and protect diversity. The operational Protocol starts with a question—*What makes the All of Us Research Program unique?* The answer is that, besides several other features, a key strength is *Diversity.* Indeed: "Participants reflect the country's rich diversity, including communities historically underrepresented in biomedical research" (Department of Health and Human Services, and All of Us Research Program 2018). The mobilization of people to donate to the AoU occurs differently from national European databases. Many European countries have older, better harmonized systems of EHRs (electronic health records) and have had national healthcare systems that broadly cover these 'underrepresented' groups and thus have had time to ameliorate their systems and correct initial problems. The American NIH only started gathering data at a later stage, thus falling behind on the international developments associated. To catch up the NIH actively tries to mobilize citizens to share their data on behalf of the program. However, this later start as well as the speed at which PPH is introduced—through direct citizen mobilization—carries along several issues.

The AoU program relies on two modes of recruitment: direct volunteering and solicited enrolment during clinical interaction. Meaning national campaigns and digital strategies were developed to recruit volunteers directly, and indirectly through their health care providers. Direct volunteering draws on the crowd-sourcing model originally envisaged by Leroy Hood and Stephen Friend when they coined P4 medicine (Blasimme and Vayena 2016, p. 182; Hood and Friend 2011). Citizens i.e. possible participants could run into the AoU campaign at different sites; they may either run into the AoU bus in their neighbourhood, find the campaign online, or are asked to join at their doctors office. On the AoU website a whole range of participating healthcare provider organizations (HPOs) are mentioned which were provided funding. The AoU speaks of "Community Engagement Partners" and refers to them as "awardees" and sub-awardees—both for-profit and non-profit institutes were awarded funding by the NIH to provide the means to engage their community with the AoU program. A long list of associations are mentioned, such as the National Association of Hispanic Nurses (Raleigh, North Carolina), the National Baptist Convention (Nashville, Tennessee), the National Council of Negro Women (Washington, DC) or National Hispanic Council on Aging (Washington, DC) to name a few and many more have been awarded funding ("Communications and Engagement Partners — All of Us | National Institutes of Health," n.d.). These are said to fulfil in an important role;

> All of Us community engagement partners serve diverse communities and help people join and stay in the program. Some also engage and educate health care professionals about the program ("Communications and Engagement Partners — All of Us | National Institutes of Health," n.d.).

Similarly other foundations, institutes and non-profits that support the AoU are called "champions" and fulfil a similar task;

> *All of Us* champions support the mission and goals of the *All of Us* Research Program by sharing information on the program with their communities to help raise awareness.

Although these awardees represent the diversity of communities that are reached out to, the relation seems to be one-directional. Communities receive money to recruit volunteers but whether they are invited to give voice to possible concerns remains unclear. However, with regards to the 'participant as partner' objective that the AoU has installed governing bodies that include a variety of members that seem to reflect some of the diversity that is mentioned;

> Since April 2018, the program's four inaugural participant representatives have been joined by 28 participants as partners for a total of 32 participant representatives across the program. They will serve on *All of Us* Research Program committees and help support the program's design, implementation, and governance. A total of 8 individuals now serve on the program's advisory and governing bodies—the Advisory Panel, Steering Committee, and Executive Committee. Twenty-two individuals provide input on specific aspects of the program, such as research priorities, participant retention, privacy and security, and the meaningful return of information to participants. Participant Ambassadors will also serve on working groups and task forces ("All of Us Participant Partners | All of Us," n.d.).

Which seem as data donors can in some ways influence agenda-setting. Currently, over 319,000+participants are taking part in the AoU program, and data continues to be collected at over 300 sites (NIH 2019). The AoU program, at the time of writing this article, has access to over 175,000+EHRs. The Self-reported ethnicity graph, posted on the AoU website as a 'data snapshot', shows that Afro-Americans for example (22%) are overrepresented compared to the entire population (of which Afro-Americans are estimated to constitute 12.7%; United States Census Bureau, n.d.), which suggests that the inclusiveness objective is indeed reflected in the data obtained so far.

The AoU program information consistently employs images that emphasise how individuals from a diverse set of cultural backgrounds, gender, age and ability are invited to join (Fig. 1). When browsing through the program's goals, protocols and images, it is hard to not think about the AoU program as having strong ideological connotations. When we recall Obama's speech on the Precision Medicine Initiative for example ("We want every American to ultimately be able to securely access and analyze their own health data so that they can make the best decisions for themselves and for their families", Obama 2015), and the NIH online material ("An opportunity to ensure that your community is included in the studies that lead to new understanding and new treatments", NIH 2018), one easily tends to see the AoU program as a very 'empowering' project indeed. Yet, although inclusiveness and empowerment are important moral objectives, data collection in itself does not empower any of the marginalized identities that are referred to. Minority community scepticism about benefits of research participation is not unjustified given a history of abuse in medical trials such as the Tuskegee Syphilis study (Brandt 1987); research data have

Fig. 1 Picture from the *All of US* research program website captioned 'the future of health begins with you' (https://allofus.nih.gov/ accessed 28 July 2020)

often been used for purposes that harmed the communities in question. The NIH's communication strategy is to change this by valorising "diversity" as a positive aspect of the shared identity of the people, thus framing it as a democratic resource for powering new public health initiatives. This might indeed lead to an increase in the quality of public health, but it may well be that, whilst other actors benefit economically from the donated data, the individuals and groups that donate the data may even be excluded from such economic benefits. This scenario that also applied to donors of biological materials in the past, e.g. the HeLa (Henrietta Lacks) cell line case (Truog et al. 2012). Additionally, example such as the heart failure drug BiDil which had a race-specific indication has shown that race-marketing is real and distorts our conceptions about race;

> The problem with BiDil is not only that it biologizes race but also that it uses race as biology to create the impression that the best way to address health disparities is through commercial drug development. By exploiting race in the service of product promotion, it distorts public understanding of health disparities and of efforts to address them (Sankar and Kahn 2005).

Considering the possible harms in using participants data it is important to address the specific characteristic of information sharing in the digital age. This first of all implies that we should carefully weigh the terminology we employ. While the term "donation" is often used in the context of organ donation or the donation of body samples (blood, urine, cells, etc.), we now live in the era of data 'sharing'. If we allow researchers to access our medical records, we can still access them ourselves. Therefore, it seems valid to consider most forms of data

transaction as 'sharing', as the person 'sharing' the data in theory continues to benefit from the data they contributed. This is why the term 'information sharing' can legitimately be used in the AoU program (U.S. Department of Health and Human Services n.d.). However, the characteristic of data that it is not consumed in the course of the process and that it can be used and reused indefinitely is reason for bio-ethicist Barbara Prainsack to argue that 'sharing' is rather unspecific and that 'data donation' is preferable (Hummel et al. 2019; Mayer-Schonberger and Cukier 2013; Prainsack 2019). Calling it 'donation' would acknowledge the relational character and the opportunities that are given i.e. to use and market them (Prainsack 2019). As Hummel et al. argue, 'sharing' obfuscates the symbolic meaning of what a gift entails; gifts are means for individuals and groups to determine and shape identities, because we give something of ourselves to others (Hummel et al. 2019). One could argue that this is precisely what participants in the AoU program are enabled to do: building a group identity via the 'gift' of their data.

Along these lines, non-economic concerns could be at stake, like in the case of Native American Havasupai people in Arizona who in 2004 provided 4000 samples for diabetes research. The subsequent DNA research violated their religious beliefs and left them vulnerable to stigmatization, as researchers looked into their tribal origins in terms of migration and inbreeding for example (Lee et al. 2019). The claim that "[t]he next great breakthrough will be found in each and every one of us. And what we find there will unlock mysteries, heal the sick and eradicate disease," moreover, is contradicted by disclaimers made about the AoU program director Eric Dishman, who emphasises that the AoU is dedicated to research, "and completely separate from medical care" (Facher 2017). So how exactly does 'diversity' play a role here? It may well be that "diversity" only offers an appealing banner, whilst the processes of data donation potentially generate class, race, and gendered exclusionary practices as they did in the past.

An article published on the AoU website called "Got DNA? NIH Bus Visits San Antonio Seeking Diverse Research Samples" shows how personal identities are entangled with the data produced within AoU (Garza 2019). The article describes the AoU program outreach: NIH visiting more than 100 cities across the nation in its light blue donation bus. The author reports an NIH visit to San Antonio and her encounter with a local:

> Jessica Corpus was walking to her next bus stop when she came across the All of Us bus in the parking lot of the Second Baptist Church at 3310 E. Commerce St. on San Antonio's East Side. After program volunteers explained the initiative, Corpus was eager to donate her biological samples. "For the longest time, I thought I was Hispanic, and that's how I identified. But I recently came to find out that the majority of my family came from the Philippines," Corpus said. "Also, my mom has been diagnosed with sarcoidosis, which we learned is a mostly black and European illness. So, I think it's really interesting how your [background] affects things like that."... Corpus told the Rivard Report that at age 38 she does not have any current health problems or concerns, but that she wanted to have her genetic

> information to pass on to her children "in case they had any problems in the future."…"I think that most people don't think about it, or are in the dark [about their genetics]. I know that I was," she said. "I think it's cool that they can track your blood and break it down to know so much about [you]. It might not be important for me to know now since I am doing good, but I want to have this information available to me and my children".

By participating in the AoU program, one is afforded the opportunity to learn more about oneself and one's family. The report vividly documents, for instance, how one particular individual, eager to learn more about herself, had to reconstitute her genetic identity, as being Hispanic and Philippina. Notably, however, the AoU research program is expected to make explicit the ways in which citizens relate to each other in terms of health. In a video called the All of Us Anthem we see how individuals are tempted to look at themselves as more than carriers of data;

> We are one nation, one people. When called upon to give from within, we come together and find that our capacity to help others is limitless. Here, we are fearless. What lies inside all of us is more than data. It's life. Its more than insight and medical research. Its vision and honor and compassion. What's flowing through Americas veins is its' diversity.
> The next great breakthrough will be found in each and every one of us. And what we find there will unlock mysteries, heal the sick and eradicate disease. We ask for one million individuals to come forward and stand on this landmark in history. We ask America to do, once again, what she has always done: lead the way forward. We're one nation. One people. But all of us are different, and it's those very differences that will lead to answers for generations to come ("The All of Us Anthem - YouTube" 2017).

The data at stake, quite literally it seems, concern life and thus make possible a heroic deed, to open up what lies inside of 'me', allowing individual participants the possibility to heal the sick and to eradicate disease. Donating data contributes to a healthy future for all Americans. The subtle merger of ideas about life and being one nation, and about diverse identities, becomes quite tangible here. Not only is 'diversity flowing through Americas veins', the video also shows the faces of a diverse group of people in the style of a documentary. And there is also a written statement that accompanies the video, saying that "All of Us is more than just a medical research program. It's the promise of positive change for generations to come". Data donation becomes the American thing to do, an expression of biological citizenship.

Another example is the video published by the AoU program to recruit participants, a short cartoon in fact, entitled 'What is All of Us'. In the animation we are encouraged to think of 'others' and what our individual contribution could mean for somebody else:

> Meet Ray. Ray lives on a farm, He loves playing kick-ball with his grandkids, but lately he's gotten a little slower, and been visiting the doctor a lot

> more often. This is Kim. Kim Lives in the city. She loves to exercise, cook healthy meals, and can't remember the last time she called in sick. They're both people. But not all people are the same. And yet when we visit the doctor, our treatments don't look that different. Why is that? Because we just don't have enough information to do it better. Until now. Enter: All of Us, the research program based on Precision Medicine…This means that Ray and Kim's children, and their children's children, can live longer, healthier lives. By becoming one of the first one million people to volunteer, you can help reshape the entire future of healthcare for generations to come… ("What is All of Us? - YouTube" 2017).

The video invokes its audience to look at themselves like 'Ray and Kim': 'I am like them and I too can contribute information for precision medicine'. Data donation becomes an expression of solidarity. Of course, 'I' want to help individuals like Ray and Kim, and eventually myself. The name of the whole endeavour itself, 'All of Us', suggest that the initiative is there for everyone (Sharon 2018, p. 5). The social value of sharing health data is emphasized (Sharon 2018). Not sharing your health data, because of self-interest, is considered morally wrong, since it damages the common good (Yakowitz 2011).

Drawing from Rose's *The politics of Life Itself*, we argue that programs designed for the collection of health data are intrinsically 'performative': they provide a certain way of imagining the individuals who are to share their health data (Rose 2007). The AoU research program mobilizes ideas about health and personhood that are constitutive for a data-sharing self. The responsible healthy citizen now contributes to health in terms of data, and sharing one's data becomes constitutive for becoming part of this community. In that way, the AoU program links a conception about citizenship to beliefs about biological existence and identity, prerequisite for the success of the data-sharing ecosystem.

The type of discourse employed by the program, together with the imagery and videos displayed on the AllofUs website, is performative in that it constitutes citizens through a so-called "somatic ethic" (Rose 2008). As Rose argues, our sense of self is closely linked to our living biological body and thus it becomes the site of hope and potential. Donating health data and getting access to them does not merely make the data donors physically better, for donating also makes the donor a better person. Novel practices of digital health are taking place within a regime of the self, where the self is constituted as an enterprising individual, actively shaping his or her life course through acts of choice (Rose and Novas 2008, p. 36). By placing it in the service of health and life, bio-capital aims to attain a hold on our economies of hope—the data-sharing subject is thus intrinsically linked to the spirit of bio-capital.

Biological citizenship in AoU entails a data-sharing individual that contributes to his or her own health, but is also a member of a seemingly diverse and inclusive society (recall the AoU anthem: "What's flowing through Americas veins is its' diversity"). AoU asks participants or partners (rather than 'subjects') to become involved and their involvement, which suggests that AoU is becoming a joint effort. This obscures an important fact: participants in this data-sharing scheme do not have

any formal power to decide what is being investigated or developed on the basis of their data, nor is access to such investigations or developments facilitated.

In an online news article entitled "restoring trust in medical research among African-Americans", Randall Morgan points out that, over two-thirds of patients at federally qualified health centres have annual incomes below the poverty line.[2] In response to a previous communication by Robert Winn, Director of the University of Illinois Cancer Center and a principal investigator on the AllofUs program, he writes:

> Winn said he sees young men who hear about a longitudinal study — "we'll be following up over the course of the next 10 years" — and who tell him, given the gun violence in their communities, they're not sure they'll live that long…

Additionally, he points out:

> Many recruitment efforts in Latino communities, for example, have to take into account the current political climate. The introduction of "we're with the federal government, we'd like to sequence your genome, we'd like your Social Security number" is not necessarily a welcome one.

The AoU research program seems promising, yet these online discussions on 'restoring trust' underscore that we should not forget what data donation actually involves, namely a non-reciprocal relationship between those on the giving and those on the receiving end. Yes, the AoU program drives its buses straight into poor neighbourhoods with promises of doing good for the community by donating data. But this does not preclude open reciprocity. Perhaps data donation should be more explicitly referred to as data-trade: you give us your data, and we, the AoU program, will commit ourselves to improving public health in your community. Even though it is widely believed that there is a requirement that researchers provide benefits to resource-poor host communities (Hughes 2012), this is particularly difficult when it comes to sharing data because such data-intensive approaches pursue open-ended purposes (Beier et al. 2019, p. 2). For now, it seems that getting access to one's own individual health data is the only benefit so far. This begs the question whether this type of data collection can live up be scaled up for PPH. In the next section we address the issue of data donation more thoroughly.

Data as the currency of life

Based on our analysis of what precision medicine tries to achieve, 'Doing good for your community' by donating health data to the AoU seems a rather nebulous phrase when that community is considered a collection of individuals that each need to make healthier lifestyle decisions, based on their unique genetic-biomarker profile and other data. In this section we will focus on the economic benefits and

[2] https://allofus.nih.gov/news-events-and-media/news/restoring-trust-medical-research-among-african-americans.

the socio-political interest involved in data research, in order to determine how this affects the bio-citizenship of data-sharing subjects.

In a previous publication we already explored a basic tension in the Precision Medicine Initiative, namely between the neoliberal demand to share personal information and the positive right to become a member of a health data-sharing community (Vegter 2018). As Devisch and Hoywegen point out, building on Baudrillard, individuals should not be seen as consumers who passively internalise marketing strategies or social imperatives, but rather as citizens that desire health. That is why 'datafication' entails a new paradigm for understanding health consumption (van Dijck 2014), while bio-citizenship may help us to understand the desire of AoU participants to share data (Rose 2001). What connects the two is the idea that data can be regarded as the currency of life. Data is represented as a natural resource consisting of health information, biomarkers, biospecimen, environmental factors and so on. Therefore, data sets not only contain information about personal identities and health risks, they are bio-capital at the same time. Yet data as the currency of life does not necessarily entail the broader narrative about human existence in contemporary society, which concerns our social existence rather than our biological life. The AoU program, as we have seen, frames participation as an opportunity to learn more about your health. It presents sharing your data as offering more choice and opportunity. The data sharing ecosystem is presented as an instrument that enables individuals to help benefit their peers. As such, the emphasis on good health as the main reason for contributing to the program can be understood as endorsing the discourse of 'healthism':

> Healthism positions the achievement and maintenance of good health above many other aspects of life and features of one's identity, so that an individual's everyday activities and thoughts are continually directed towards this goal. A dominant belief underlying healthism is that fate can be controlled, at least to some extent, by personal action and the taking of responsibility for one's health (Crawford 1980, 2006; Lupton 2013, p. 397).

Lupton points out that healthism like in the AoU discourse tends to gloss over the social and economic determinants of health states by emphasising 'taking charge' of one's own health. It seems as if the empowerment rhetoric is common language for any sort of biobank initiative that relies on citizens sharing their data, such as 23andme (Lucivero and Prainsack 2015). But again the question is, if citizens obtain the right to become a member of the data-sharing community, will they also be included in the process of agenda-setting and defining PPH policies?

We are accustomed to the idea that life holds value, for instance in religious or in ethical terms, but the definition of life's value in economic terms is less obvious. Life is of value to specific actors with specific interests. This applies to plant or animal life, but it may apply to human life as well. In the case of precision medicine, human life has value not in terms of the economic productivity, but rather in terms of the predictors of functioning, health and behaviour. In this regard, detailed bio-information has become an issue in the economic game between governments, technology innovators, scientists, industry, insurance companies and health care professionals. And in this sense, yes, data has become

the currency of life. The AoU program sees data as a natural resource that lies in each of us, making us co-responsible for our own self-surveillance (Rich and Miah 2014, p. 299). Citizens are called upon to look at themselves as carriers of data. The biomedical institutes that collect and 'refine' these data will hand back an interpreted version of themselves.

In portraying data as a natural resource, Barbara Prainsack explains, the metaphor achieves three things. First of all, it places those who refine data in a position where they have a moral right to profit from that data because they developed the infrastructures and tools to make data usable. Secondly, it renders invisible the contributions that people make who donate the data. Thirdly, it portrays commercial corporations as fulfilling an important societal function, namely to create and analyse important evidence about the world, stressing the allegedly depoliticized and de-contextualized nature of data. However, based on our analysis so far, if data sharing takes place in name of collective well-being and solidarity, what can contributors expect to receive in return from initiatives such as the AoU in terms of public health? How will this gift-relationship benefit their own health? As Prainsack points out, the idea that data is being donated like a gift, underscores the relational nature of such donations:

> despite donation not being a commercial transaction, and despite their not being directly reciprocal in the sense that you do not need to give me something directly in return, my donation articulates, strengthens, or changes my relation to the person or entity that I donate something to, and vice versa (Prainsack 2019).

This unique data-donation relationship is conceptualized by Prainsack as *indirect reciprocity*. It emphasises that data donation has an inherently trust-building feature. But how does this work out in the relationship between the data-sharing subjects and the public–private partnerships in the context of AoU? What we notice, once again, is that bio-citizenship is defined primarily in terms of data, in terms of bio-capital even, which justifies thinking about participating individuals in terms of consumption and production. The focus is on 'bio', rather than on 'citizens', on the mobilisation and exploitation of resources, rather than on benefit-sharing and co-productive agenda-setting. If that is the case, then the objective to reach out to vulnerable communities could be explained as 'data colonialism', driven by the need to disclose new resources (Greene and Joseph 2015, p. 224; Sadowski 2019, p. 3). Inclusivity and diversity are then reduced to opening up new markets to allow for economic growth. Considering the objective to develop PPH, this framing of human subjects as biological data reservoirs (who can only act responsible by sharing their data), fails to do justice to the 'public' dimension in public health and to the 'citizen' dimension of bio-citizenship.

Conclusion

In this paper we investigated the objective to facilitate PPH based on data shared for the AllofUS research program. PPH is an emerging idea to harness the data collected in the program for preventive interventions for at-risk groups. The perceived risk of PPH is that it may allow further marginalisation of groups that were previously underrepresented in biomedical research. On the other hand PPH might be a way of embedding a form of 'indirect reciprocity' that we argue is appropriate considering the way data is shared under the guise of doing good for your community. Yet we observed some major challenges. The gift relationship has become a way to harvest data and to generate surplus value for information concerning specific groups, but it remains fairly limited how participants (notably from vulnerable populations) can have a say in the use of the insights thus gained. While distrust for data sharing practices seem legitimate given the lack of protection by HIPAA described in the consent form, individuals are nevertheless inclined to 'share' their data on behalf of precision medicine. To get a better understanding of why the individuals would be motivated at all to donate personal information, we have foregrounded a specific notion of biological citizenship. Because biological identities are intrinsically related to the objectives of the PPH and expressed in the public materials published by the AoU, donation would become a form of ethical self-expression and civic as well as community solidarity. Yet where the recruitment tactics focuses on 'citizenship' in terms of empowerment (front), it is the 'bio' prefix that has become the main focus in terms of research. PPH can in principle be used to understand and address broader societal issues but this requires more than precise identification of at-risk-groups. Thinking in terms of citizenship stresses the importance of a 'reinvigoration' of solidarity as a key principle in bioethics (Chadwick and Berg 2001; Mulvihill et al. 2017; Prainsack and Buyx 2011).

Compliance with ethical standards

Conflict of interest On behalf of all authors, the corresponding author states that there is no conflict of interest.

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